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# **Illness as transformative experience: Implications of philosophy for advance care planning**

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## **Abstract**

Advance care planning has been shown to improve patient outcomes and is recommended as part of routine care for people with a life-limiting illness. Nevertheless, developing an advance care plan can be complex and challenging for both patients and family members, and the clinicians who support them. One complexity is that illness and its treatments often cannot be deeply understood without lived experience. In this paper, we explore this idea, highlighting how lived experience can bring about unpredictable changes in an individual's values and preferences. We examine the implications of such 'transformative experiences' for advance care planning, using the hypothetical case study of Jean, an older person with advanced kidney disease. Finally, we consider consequences for clinical practice and how an understanding of transformative experience might enhance current approaches to advance care planning.

## **Key words**

- Advance care planning
- Philosophy
- Transformative experience
- Shared decision-making
- Illness experience
- Phenomenology

## **Running title**

Transformative experience & ACP

## Introduction

Advance care planning (ACP) is “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care”.(1) ACP is recommended as part of routine care for people with a life-limiting illness, is endorsed by professional bodies and incentivised in healthcare funding.(2-7) There is evidence that ACP can be of benefit in terms of patient satisfaction with care, death in preferred place, healthcare savings, and family mental health after death.(8, 9)

Notwithstanding these benefits, developing an advance care plan can be complex and challenging for both patients and family members, and the clinicians who support them. Those involved confront their mortality, consider upsetting scenarios and must consider and apply their beliefs and values to plan for their futures.(10) It is therefore unsurprising that barriers to ACP have been documented.(9, 11) Clinicians can struggle with discussing future deterioration and death and can be uncertain of their role in ACP and how best to support the process.(12, 13) However, these complexities are rarely discussed in the literature.

Turning to the Humanities, specifically philosophy, can help. In this article we draw on L.A. Paul’s concept of a ‘transformative experience’ to explore the challenges inherent to ACP. Paul defines a transformative experience as one which teaches a person something that could not otherwise have been known, and in doing so deeply changes them.(14) Two examples are becoming a parent and fighting in a war. We use the case of Jean, an older woman with advanced kidney disease, to demonstrate how illness can also be transformative, and explore the implications of this for ACP. We highlight some limitations of current approaches and consider lessons for clinical practice.

## Jean

*Jean is an 85-year-old retired schoolteacher. Following a pneumonia two months ago, her physical health is significantly impaired. She finds herself largely confined to the house. She eats, washes and dresses independently and enjoys her “quiet life”. Brian, her husband, does most of the household tasks.*

*Jean needed haemodialysis during her admission. Whilst this was only temporary, her kidney function remains very diminished and continues to fall. She was told that she is likely to develop kidney failure within the year.*

*Jean's kidney specialist invites her and Brian to an appointment to plan for this possibility. She tells Brian before the appointment that she thinks she wouldn't want intrusive interventions were her quality of life to deteriorate significantly, but she is struggling to imagine what the future might hold and how she might feel if she were more seriously ill. She has never discussed her life expectancy with a clinician, but has begun to wonder how much longer she has left.*

### **Advance care planning – need and purpose**

Jean's upcoming consultation will focus on how she would prefer to prepare for the possibility of end-stage kidney disease. Well-facilitated, this will be embedded within discussions of where she is in her life and what the future might hold.

Jean is likely to be in her last few years. Her health may decline further before she dies.<sup>(15)</sup> She is at risk of sudden death, acute illness and hospitalisation. Her capacity to engage in healthcare decisions could become impaired at any point: either acutely and temporarily, or progressively and enduringly. Brian's support would be compromised were his health to deteriorate. Without him, she might need professional care, or a supported living environment. End-stage kidney disease could arise following progressive loss of kidney function, or as a complication of acute illness. Deciding whether to make preparations for dialysis or to opt for 'comprehensive conservative care'<sup>(16)</sup> (a palliative care approach) before onset of end-stage kidney disease is recommended.<sup>(17, 18)</sup> Such discussions bring to the fore the trade-offs made when deciding whether to take on intensive medical treatment towards the end of life. However, the issues raised are relevant to people facing other healthcare decisions "*at any age or stage of health*".<sup>(1)</sup>

The goal of ACP is to ‘*help ensure that people receive medical care that is consistent with their values, goals and preferences*’.(1) Deep, open discussions about Jean’s preferences for medical treatments, her values and life goals might help her to plan for potential futures. Sharing these with Brian and the medical team could inform clinical decisions were her capacity to become impaired. The ensuing advance care plan could profoundly influence the duration and nature of Jean’s remaining life. However, her experience of illness and of the interventions discussed is likely to be transformative, complicating the ACP process.

### **Illness as transformative experience**

*“What’s in store for me in the direction I don’t take?”* — Jack Kerouac, ‘The Subterraneans’ (1958)

Illness can be epistemically and existentially transformative: it is impossible to know what it means to live with life-limiting illness without personal experience, and such experience can be so profound that core values are fundamentally altered. People with serious illness undergo epistemic transformation, as they learn what it is like to receive a diagnosis, cope, and undergo medical intervention.(19) Through their experience, they can be altered in unimaginable and unpredictable ways, and may see their career, familial and societal role, ambitions and worldview change – undergoing existential transformation.(19) For those with poor prognosis, this includes confronting mortality and the ‘ultimate personal transformation’ of death.(14)

Empirical evidence of such transformations exists. Individuals with severe illness consistently rank their wellbeing higher than healthy controls asked to imagine living in a comparable state.(20) People visualising health states overestimate the affective impact of negative events because of focalism – imagining negative events in isolation, and immune neglect – discounting the potential to positively reinterpret these negative events.(21, 22) Focalism and immune neglect may even apply when individuals consider their own death. People who are approaching the end of life view death less negatively than those for whom it is further away.(23) A related phenomenon, response shift, is defined as a change in the meaning of self-rated quality of life as a result of a modification of internal standards of measurement (recalibration), values, or definition of life quality (reconceptualisation).(24)

Response shift is well-documented in life-limiting illness, in which it can result, for example, in preserved quality of life despite declining physical function.(25-27)

For Jean, the future includes potential experiences that are impenetrable without living them, including irreversible cognitive decline, starting dialysis or living on after Brian's death. Each may see Jean's world view change so significantly that her very person is altered. This potential for transformation has implications for the process and meaning of ACP.

### **Planning for transformative futures**

*"Life can only be understood backwards; but it must be lived forwards."* – Søren Kierkegaard, 'Journals IV A 164' (1843)

Jean faces the challenge of applying her current values to decisions about future events. Such an approach cannot ensure that she receives medical care *'consistent with her values, goals and preferences'*(1), because these very values, goals and preferences may be transformed by the experiences that lie ahead. To deny this is to fall prey to the 'end of history' illusion: the psychological tendency to believe that in the future we'll be no different from who we are today, despite evidence in our own lives of the contrary.(28)

Transformative experiences pose a challenge for normative decision-making, which casts individuals as rational agents making choices in a way that endeavours to maximise future fulfilment.(29) In these models, decision-making involves weighing-up the perceived benefits of available options, before choosing the most favourable. Rational individuals must therefore project futures based on choosing different options and apply their personal values to imagine how each would feel. However, where futures include transformative experiences, prospective estimation of wellbeing becomes impossible. Furthermore, the choice itself determines whether an individual undergoes transformation, yet existential transformation means the 'self' who has the experience is different from the one deciding whether to have it. Paul calls this 'transformative choice' and Jean, like many individuals undertaking ACP, faces one now.(14)

### **Jean's perspective on ACP**

*After discussing options with her kidney specialist, Jean is confused. Planning for dialysis seems to be choosing a different kind of life from that which she has lived. Meanwhile, opting for conservative care would mean a radical shift in her aims, ambitions and relationships. Jean wants to live, but quality of life is essential to her. She has a friend who seems to have coped well with the life changes caused by dialysis, but she's not sure how similar they are in temperament, or what kind of person her friend was before her illness and treatment. Jean is struggling to decide what is right for her.*

Jean's uncertainty regarding ACP demonstrates the difficulty of making a transformative choice. Some people faced with Jean's decision have a clear preference for one care or treatment plan over another; they might be strongly committed to avoiding life-prolonging treatment towards the end of life or to continuing with it for as long as possible – regardless of the transformative nature of the illness and treatment ahead of them. Such convictions might come from deeply-held beliefs, religious or otherwise, or previous experiences. In the absence of such convictions, Jean is trying to weigh-up the futures available to her. In doing so, she must base her decision on something unknowable. Who will she become and what will her lived experience be if she chooses dialysis or comprehensive conservative care? How will she and her family cope with and integrate her chosen care into their lives?

Jean's values, preferences and life experience feel insufficient to choose one course of action over another. She recognises that her default sources of information – accounts from those who have undergone similar experiences – may be misleading. If these individuals have undergone transformation, their values may have changed. Their accounts are mediated through their new worldview and may not be relevant to someone who has not yet lived such an experience.

### **Jean's doctor's perspective on ACP**

*Jean's doctor provided her with evidence on quality of life and longevity with dialysis and comprehensive conservative care. Dialysis will most likely extend her life, but this is not guaranteed, and it involves significant treatment burden.(30) Even with dialysis, Jean is unlikely to live for more than short years.(31) Dialysis initiation is*



*associated with a sharp decline in functional status amongst the frail older population.(32) Dialysis does not appear to be better at controlling symptoms than conservative care.(30) Deep down, Jean's doctor thinks that conservative care is most likely to offer Jean the best balance of quality and quantity of life. However, only Jean can decide what is best for her, and, unable to recommend a course of action, her doctor feels uncertain how to offer support.*

Here, as is often the case, empirical data does not suggest one treatment is unequivocally better than the other. Decisions in such contexts are 'preference sensitive': treatment attributes and outcomes need to be viewed through the lens of the patient's values and preferences.

Shared decision-making has become the prototype for supporting such choices, and Jean's doctor is keen to engage in it.(33) Yet, its application does not necessarily simplify the situation. Shared decision-making sees clinicians eliciting values and preferences surrounding a choice, providing bespoke evidence regarding likely outcomes and helping their patient to apply what is important to them when choosing the best course of action. The relevance to ACP is plain. However, even sophisticated interpretations of shared decision-making in chronic illness settings do not circumvent the problem that ACP involves transformative choices.(34) A disconnect between current values and future health states remains, undermining attempts to define decision-making as a matter of rational choice based upon personal preference. Experienced clinicians are likely to have cared for many patients who have experienced a change in values following exposure to previously intangible health-states and treatments. Many will be familiar with the inability for current preferences to predict future wellbeing. Nevertheless, conventional descriptions of shared decision-making do not provide clear guidance for clinicians or patients striving to apply the appropriate preferences to a 'preference sensitive' situation.

### **Implications for practice**

What, then, does all this mean for humanistic clinicians supporting individuals making complex ACP and treatment decisions? We suggest four main implications. Firstly, we must recognise that for many patients, ACP is an existential act. The usual resources individuals have drawn upon in a life of decision-making – including others' experiences and personal

encounters with similar events – might be of limited relevance. Even perfect population-level evidence is unlikely to diminish the complexities of life-or-death decision-making.

Secondly, we must appreciate the transformative nature of illness. We should introduce this element of increased uncertainty when discussing options and future scenarios with patients.<sup>(19)</sup> However strong our own convictions about the best course of action, we cannot know how the individual in front of us will fare. By recognising that many of the choices patients face are transformative – and that, ultimately, we all plan for fundamentally uncertain futures – we bring our humanity and humility into the support we provide.<sup>(35)</sup>

Thirdly, we must consider the phenomenon of adaptation when considering future illness and treatment. This will be foreign to some clinicians and patients. We should discuss this possibility, and in doing so provide new ways of imagining the future. We can share evidence showing that most people can adapt to chronic illness and continue to live meaningful and content lives. As Carel and colleagues point out, the notion of transformative experience can thus be used as a springboard for discussions about putative futures: reducing certainty about the future opens the door to more uncertainty, but also to the possibility of *“imagining a fulfilling life which is not socially scripted or the life the patient has wanted, but could nonetheless be a rich and satisfying life.”*<sup>(19)</sup>

Finally, we must ensure that advance care plans are flexible and regularly revisited, to accommodate changes in patients’ preferences, goals and clinical situations. ACP should primarily be about communication and the process of a patient becoming aware of and sharing their preferences and what drives them.<sup>(11)</sup> It must not be perceived as making concrete plans for care in the unpredictable future.

### **Jean’s end of life**

*Jean was never able to decide whether she should prepare for dialysis or choose conservative care. However, the ACP discussions did help her to find a new way of talking about the future. She subsequently developed cognitive decline and became less able to engage in complex care discussions. She remained able to voice her dislike for “fuss” and medical intervention. Whilst Brian wanted her with him for as long as possible, it was clear that Jean’s preferences were for gentle, loving care only.*

*Blood tests were discontinued and a plan to minimise hospital admissions was made. Community palliative care input enabled her to stay at home and continue to enjoy her “quiet life” until she died with Brian beside her, 11 months after her first admission.*

## **Conclusions**

Contemplating ACP through a philosophical lens, we have shown how considering illness as a transformative experience can shine a light on both patients’ and clinicians’ experiences of planning future treatment. ACP involves transformative choices, which challenge individuals to act in ways that will maximise the chances of a fulfilling, valuable life, whilst looking within themselves to see what they really want and who they are. Paul argues that when making such choices it is difficult to be true to oneself, because the experience involved is both radically new and will most likely change core personal preferences.(14)

This perspective erases any conception of ACP as a simple process. Because of what it asks an individual to do, ACP is rarely a case of computing the best course of action. Rather, it involves a complex process of imagining how one might change in the future, and what one’s values, preferences and best interests might then be. But ultimately, to quote Paul: *‘our desire to own our futures when we face such choices, a desire that is expressed by the way we reflect and deliberate over which life’s path we want to take, cannot be satisfied’*.(14) Combining our personal values and preferences up to this point in our lives with the obtainable evidence may be the only strategy available – but this often means there is no definitive ‘right’ decision. Changes in our own preferences and values are highly likely as we grapple with inevitable uncertainty.

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Jean's story is fictional. Any similarity to another person merely reflects how common it is that we must confront and plan for our own future health, illness and end of life.

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